



MESOTHELIOMA UK

CHARITABLE TRUST - 1126083

Report for: Health and Wellbeing Scrutiny Commission

Meeting Date: 29th October 2015

Subject: Mesothelioma UK Charitable Trust

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Background

What is Mesothelioma?

Mesothelioma is a cancer of the lining of the lung or the abdomen caused by asbestos.

About asbestos

Brown and blue asbestos have not been imported into the UK since 1985 and white asbestos was banned in 1999.

It is the ability of asbestos to resist heat and fire that resulted in it being widely used in industry

Who is most likely to have been exposed

It is through their work that many people have been exposed.

This includes:

Carpenters, joiners, boiler, pipe and heating workers, shipbuilding/shipyard workers, Navy seamen, dockworkers, ladders, mechanics, plumbers and gasfitters, roofers, construction and demolition workers and of course people who worked in the manufacture of asbestos itself.

Is asbestos still present today

Asbestos is still present in buildings and equipment built or produced before the ban.

Asbestos is only a risk if you disturb or damage it and cause fibres to be released into the air. If you have been exposed to asbestos at any time you are potentially at risk although the majority of people who have been exposed do not suffer ill health as a result. There is no way of identifying who or why some people go on to suffer and others remain unaffected.

Incidence

In the UK about 2,500 people are diagnosed every year with mesothelioma and the UK has the highest incidence worldwide

Annually there are 30 new cases diagnosed with Mesothelioma within Leicestershire and Rutland. University hospitals of Leicester sees a total of 150 new referrals annually as many are referred into the service from outside of Leicestershire.

Currently there is no cure but the mesothelioma medical community continually strives to find better treatments to help manage the disease.

Different treatments can be used to treat mesothelioma including surgery, chemotherapy and radiotherapy and now there are an increasing number of clinical trials to give better evidence for how best to treat the disease in the future.

The Charity

Mesothelioma UK was launched in 2004 with financial support from Macmillan Cancer Support - financial independence came in 2009 when the Mesothelioma UK Charitable Trust was launched

Mesothelioma UK Charitable Trust is a national charity, hosted by University Hospitals of Leicester, with the office based at Glenfield Hospital. There are five trustees.

The operational team comprises of:

- Director of Services / Nurse Consultant
- Business Development Manager
- Fundraising Manager
- Helpline Co-ordinator / PA
- Welfare / Benefits Adviser
- Administration Assistant
- Website Administrator

This equates to 4.9 WTE (whole time equivalent) paid staff.

The main aim is to provide support to those affected by mesothelioma by providing impartial, up-to-date information and advice, access to specialist advice through the free phone helpline, the website and printed patient information.

Specialist Nurses

When Mesothelioma UK started it aspired to establishing mesothelioma nursing services in key locations in the UK – it recognised that this was fundamental to improving access to specialist care and support for mesothelioma patients.

The 1st specialist nurse post was the Consultant Nurse / Director of Services - Liz Darlison - she secured the original funding and set up Mesothelioma UK.

We now have funding available for 12 specialist nurses.

Currently posts are funded at:

- Leicester
- Portsmouth
- London 1
- Bristol
- Oxford
- Cardiff - vacant
- Sheffield
- Manchester
- North-East
- Glasgow
- Cambridge – vacant
- London 2 – vacant new post

The charity funds 2 days per week of each post and each post-holder has local, regional and national mesothelioma specific responsibilities and this costs the charity around £22,000 per year for each nurse.

The ultimate aim is to fund a total of 18 specialist nurses in England, Scotland, Wales and Northern Ireland.

MUK are currently inviting expressions of interest from trusts to realise post holders for all 12 posts.

Benefits and Compensation

The charity works closely with the Leicestershire CAB and funds a national Mesothelioma welfare adviser for 3 days a week, the hours have recently been increased in line with increased activity. The adviser is able to provide expert advice and guidance, as well as assisting in the completion of forms.

Specialist Information

In conjunction with health professionals within other organisations, Mesothelioma UK has produced specialist information on all aspects of Mesothelioma. This includes information about the disease, treatment, diet, benefits and compensation.

We have also recently launched a patient information DVD, this is available as a disc and will soon be available to view on our website.

All information is free to patients, carers, general public, health professionals and health care providers.

Supporting Research

The charity will over the next 2 years fund mesothelioma research projects in conjunction with the British Lung Foundation, this will total £300,000 over the 2 year period.

The charity is also supporting transport costs for the MARS2 trial to facilitate recruitment to the trial, as many patients may have to travel outside their locality to access treatment

Events

Action Mesothelioma Day – this is held yearly in July at Leicester Cathedral and is a service of hope and reflection. Speakers are invited along with dignitaries from Leicestershire and also patients and carers. The service is followed by a tea and cake. The Mesothelioma UK team are all in attendance.

Patient Carer Day – annual event held in October at a location within the UK. This year's event was held in Stratford upon Avon. This year the day was fully sponsored.

The event aims to give mesothelioma patients, carers and relatives the chance to meet and share experiences with others, to give up-to-date, unbiased information about mesothelioma and to give patients, carers and relatives the chance to raise issues and ask questions.

Patients, relatives and friends can attend free of charge. The topics are wide ranging and include patient stories. The day is always well received

Fundraising

The current fundraising target is **£550,000** for the 2016/17 year and for a small specialist charity this is quite a task. Year on year MUK strives to achieve its aims and priorities and to provide services that are appropriate, useful and accessible.

The charity relies totally on donations which makes up 80% of our income, the remaining is through sponsorship.

Many people are kind enough to donate to the charity and others work hard to fundraise

Our fundraisers are fully supported by us and we can provide fundraising items in the form of a pack suited to the type of event e.g. running vests, t shirts, pins, trolley keys etc.

Local context

Glenfield Hospital is seen as a centre of excellence for the treatment of Mesothelioma. There exists a team of highly skilled surgeons and oncologists for delivery of treatments.

Patients living locally have direct access to these services; Glenfield hospital also receives referrals from outside Leicestershire both for treatment and those seeking a second opinion.

Any patient attending locally has direct access to the expertise of the Leicester based Mesothelioma Nurse Specialist as well having all the information available at the clinic. They are also able to have face to face contact with the Mesothelioma UK team as required

Locally patients and carers are able to have face to face consultations with the benefits / welfare adviser, this may also include home or ward visits as required.

The benefits and compensation system can be very daunting for both patients and carers, especially after the shock of diagnosis, having someone who can guide them through this is invaluable.

Local support – rather than having a support group a monthly luncheon club is run jointly by Mesothelioma UK and University Hospitals of Leicester lung specialist nurses. The group includes both Mesothelioma and lung cancer patients and their carers.

It provides a social setting where they can meet others with same or similar diagnosis and share their cancer journey. There is a specialist nurse available to deal with any clinical issues if necessary.

The “base” for this group is Greenacres Restaurant, The Sidings, Leicester.

The feedback from all is always very positive and locations have included:

- Rutland water
- Houses of Lords
- Skegness
- Leicester Steam Railway
- Santa Special at Christmas
- Archery Class
- Garden Centres
- Mount St Bernard Abbey

The day includes lunch and most events are free to all attendees. Occasionally if a coach is required for longer distance venues then a small charge may be made to cover travel costs.

There are quarterly meetings held at the “base”, speakers are invited to discuss varying topics, these maybe medical or non-medical. Topics are those requested by attendees. We have hosted a Thoracic Surgeon, a Pain Specialist a Dietician, an Oncologist, a Trials Nurse, Alternative Therapists, and anybody we feel can enhance and help the patient journey.

Patients and carers have expressed they feel more supported and less isolated by meeting others in the same situation, it makes them feel normal again and, that their disease is no different to others, who are managing long term conditions such as diabetes. They say it also helps them to feel more confident to talk in a social setting rather than clinical and they leave feeling positive, motivated and inspired by having shared their experience.

By taking part in the social activities that MELU facilitate, does empower them to realise they can actually do more than they think they can.

The group is currently supported by University Hospitals of Leicester Charitable funds, the attendees also periodically fund raise to support the activities and raffles are held to boost funds

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